

WASHINGTON D.C. IS LISTENING

Last month there was a lot of talk in D.C. and it wasn't the typical political rhetoric. Down syndrome has been a big part of many of the conversations. Personal visits with legislators, a research summit, as well as legislative committee meetings and hearings have brought Down syndrome to the minds of policymakers throughout our nation's capitol.

NDSS Leadership Summit

At the beginning of October the National Down Syndrome Society hosted a Leadership Summit with over 250 Down syndrome advocates from all over the United States. The culmination of the three-day event was a visit to the Capitol where participants met with their local legislators to speak about the lives of individuals with Down syndrome. The message was that policy issues often are the one thing that holds people with disabilities back. Those dealing with aging and health issues tell us that policies can often be barriers to appropriate services and supports.

NIH Research Summit on Dementia

In mid-October, the National Institute of Health sponsored a two-day summit on dementia. It provided an opportunity for investigators of various matters related to care, services and support to share brief overviews of their findings and recommendations for future research. Although there was little mention of research focused on individuals with Down syndrome, Tamar Heller, PhD, shared that more than 33,000 older adults with Down syndrome live at home with their aging caregivers. As a result there is a greater role for siblings in assuming care. She also spoke about the necessity to bridge the Devel-

opmental Disabilities and Aging networks. This is becoming more and more evident as traditional Home and Community Based Services Medicaid Waivers programs no longer meet the needs of individuals with Down syndrome and Alzheimer's. If you would like to view the video of the Research Summit it can be found online. <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>

NAPA Council Meeting

In the fourth week of October the National Alzheimer's Project Act Advisory Council met where Matt Janicki, NTG Co-chair, Mary Hogan and Jadene Ransdell, NTG Family Advocacy Co-chairs spoke on the importance of the inclusion of people with Down syndrome in all aspects of the national plan. You can read their remarks or watch the video of all public comments from the Department of Health and Human Services website. <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Oct2017>

Senate Special Committee on Aging

Earlier in the week of the NAPA Council meeting, Dr. Tamar Heller of the University of Illinois at Chicago was invited to testify before this Senate committee to discuss aging with disabilities, including family caregiver issues, family supports and health promotion interventions for older adults with intellectual and developmental disabilities.

Our voices are being heard. But we must continue to share our stories.



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Let Our Voices Be Heard

- Adults with Down Syndrome are at high risk for Alzheimer's
- Family caregivers face unique challenges
- Services & supports may be difficult to find
- Share your story—email Jadene Ransdell at: jadeneransdelalz@gmail.com

OH MY GOODNESS...



Research in the United States for HIV/Aids is funded at \$2,500 per person.

Funding research for Down syndrome at approximately \$111.00 per person makes those dollars only .01% of the National Institute of Health's annual budget.

Those are facts shared in a recent bipartisan hearing of the House Appropriations Subcommittee on Labor, Health and Human Services, and Education. The room was filled to capacity with self-advocates, families, researchers and senior members of Congress (who are also parents of children with Down syndrome). This important day marked the very first time a hearing was held on current and anticipated research funding priorities related to Down syndrome. Those who spoke made a very clear case that this research is not only good for people with that extra copy of the 21st chromosome, but for all people.

Throughout the hearing, members of the subcommittee spoke about how their lives had been changed because they

knew someone with Down syndrome. The star of the hearing was self-advocate Frank Stevens who said, "There is a notion being sold around the world that we don't need research concerning Down syndrome." He spoke about the attitude in some countries related to selective termination of pregnancies involving babies with Down syndrome as a "view that is deeply prejudiced by outdated ideas of life with Down syndrome. I have a great life, I've been to the White House twice and I didn't have to jump the fence either time."

When asked what it will take to move society, the medical profession, and scientists forward in this area, one speaker responded that money indicates where values lie. When more dollars are leveraged in research in this area, more people will understand the value that we already recognize. As Frank Stevens said, "I am a man with Down syndrome and my life is worth living."

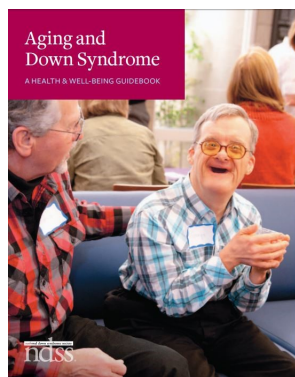
The hearing closed with a commitment from the subcommittee to "figure out a way to add money to the NIH budget."

“I am a man with Down syndrome and my life is worth living.”
Frank Stevens



BOOKS ON OUR RADAR

In each issue we want to bring you information that we have found useful to other family caregivers, as well as links to materials that are current and timely.

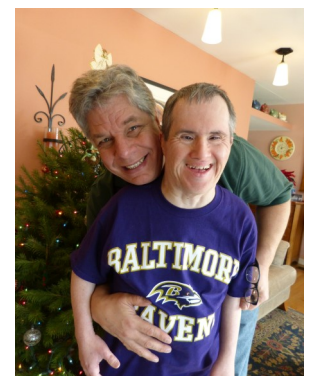


Many people, world-wide, have found great value in the first National Down Syndrome Society publication, *Aging and Down Syndrome A Health & Well-Being Guidebook*. This groundbreaking resource for families and caregivers of adults with Down syndrome covered medical issues commonly encountered in adulthood, as well as how to provide person-centered care.

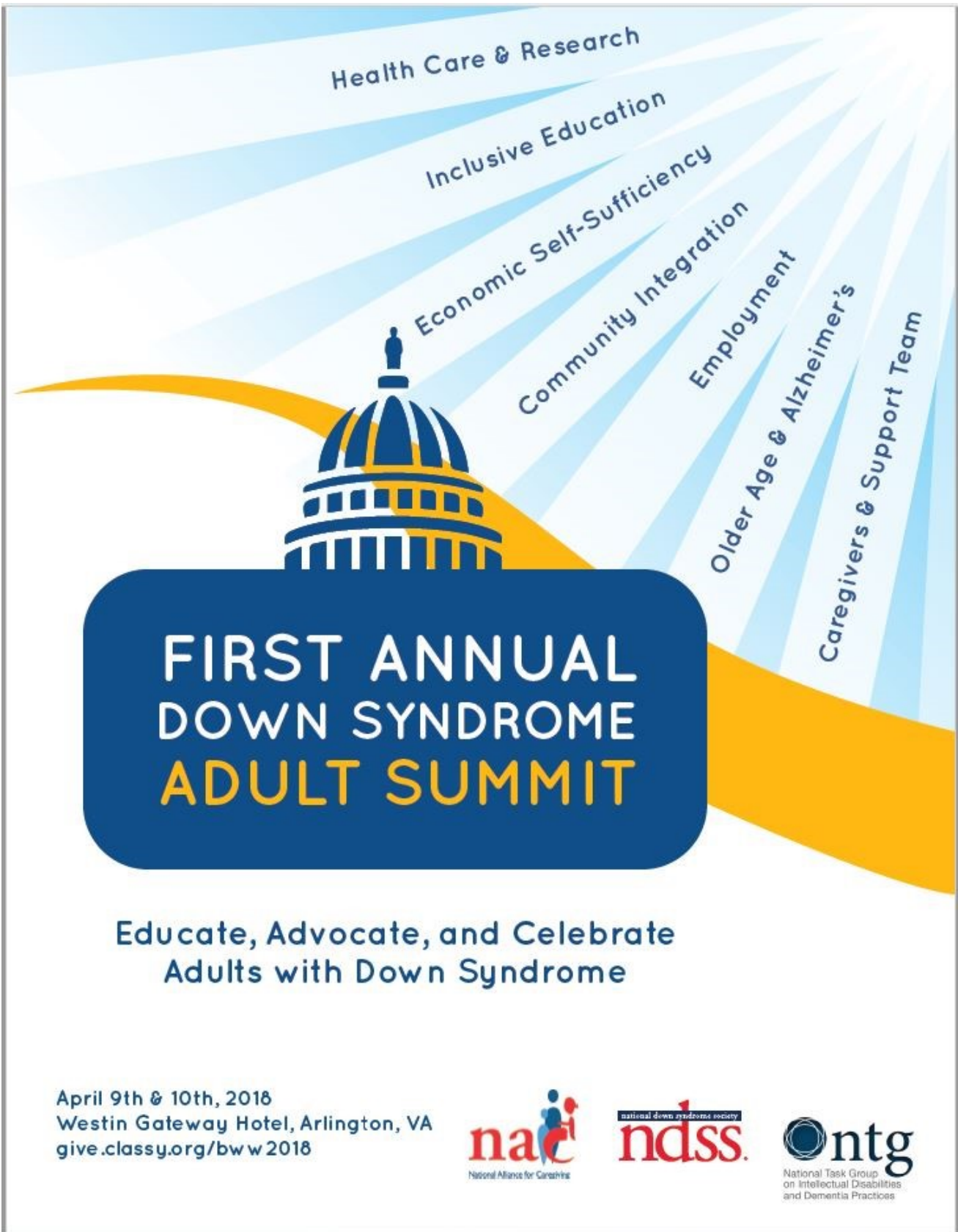
<http://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf>

For those wanting to know more about Down syndrome and Alzheimer's, the much anticipated NDSS publication, *Alzheimer's & Down Syndrome A Practical Guidebook for Caregivers* will soon be available. According to NDSS staff, the new book is in final edits as we go to press. The content of this new book covers

topics such as the connection between Down syndrome and Alzheimer's disease, the importance of baseline assessment, arriving at a diagnosis, and the natural progression of Alzheimer's disease. It also includes practical tips for maintaining meaningful activities, caregiving guidelines, caregiver stress, as well as end of life issues. For more information about this publication contact Colleen Hatcher at chatcher@ndss.org.



David & Joe, 55,
at home in Maryland



Health Care & Research

Inclusive Education

Economic Self-Sufficiency

Community Integration

Employment

Older Age & Alzheimer's

Caregivers & Support Team

FIRST ANNUAL DOWN SYNDROME ADULT SUMMIT

Educate, Advocate, and Celebrate
Adults with Down Syndrome

April 9th & 10th, 2018
Westin Gateway Hotel, Arlington, VA
give.classy.org/bww2018



DOWN SYNDROME ADULT SUMMIT INFORMATION

The Program

The **2018 NDSS Down Syndrome Adult Summit** is a conference hosted by the National Down Syndrome Society (NDSS) and its Self-Advocate Advisory Board (SAAB) in collaboration with the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) and the National Alliance for Caregiving (NAC) to discuss important and critical topics for all adults with Down syndrome. Speakers and topics will align with NDSS' robust and comprehensive programs and pillars, including healthcare and research, inclusive education, community integration, economic self-sufficiency as well as employment and our NDSS #DSWORKS® Campaign. ***Aging-related changes and health issues, including Alzheimer's disease, will also be covered.*** Join us for a day and a half and meet other families who share your journey. Topics of interest include the following:



• Healthy Aging	• Common Medical Conditions in Adults with Down syndrome
• Creating and Sharing Life Stories	• Caring for the Caregiver
• DS Connect: Research Opportunities for Adults with Down syndrome	• Screening, Diagnosis and Stages of Alzheimer's Disease
• The Role of Siblings in the Life of a Person with	• Tips for Caregiving
• Pain and Cognitive Disabilities	

The Location

The 2018 Adult Summit will be held at the [Westin Arlington Gateway Hotel](#), 801 North Glebe Road, Arlington, Virginia 22203. To confirm a space in the NDSS room block at **\$239 per night** at the Westin Arlington Gateway, please call **888-627-7076** and mention "NDSS."

The Cost

The cost for the **2018 Down Syndrome Adult Summit** on April 9-10 is **\$50 per person**. Adults ages 18 and up are welcome to attend. [Register today.](#)

The NDSS 2018 Buddy Walk on Washington

Annually, the NDSS hosts a two-day advocacy conference that brings the Down syndrome community together to advocate for legislative priorities that directly impact the lives of people with Down syndrome and their families. During the first day of the conference, advocates receive training. They head to Capitol Hill on the second day to meet with Members of Congress and their staff to discuss legislative issues that would advance education, research and healthcare opportunities for people with Down syndrome. This year, the **Buddy Walk on Washington** will follow immediately after the **Down Syndrome Adult Summit**. We encourage you to stay over to meet with Federal Legislators with other Down syndrome advocates.

The cost for the **2018 Annual Buddy Walk® on Washington Advocacy Conference** on April 10-11 is **\$50 per person**. All are welcome to attend. Children age 5 and under are free. [Register today.](#)

2018 Annual Buddy Walk® on Washington: [Pre-purchase your bus ticket](#) to Capitol Hill from the Westin Arlington Hotel on April 11. **Cost is \$10 per person.** (This is a one-way ticket.)

[Register for both the 2018 Annual Buddy Walk® on Washington and 2018 Adult Summit and receive a \\$20 discount upon checkout!](#)

LET'S TALK AGING

Many adults with Down syndrome are pioneers. Just a few decades ago, the life expectancy of a baby born with Down syndrome was 25 years. Today a baby with Down syndrome can expect to live for 60 years or more. With longevity comes aging issues that were not previously seen, and older adults with Down syndrome are leading the way to help us understand what happens as they age.

In addition to normal aging, adults with Down syndrome experience accelerated aging. They may face aging issues as much as twenty years earlier than someone in the general population.

First and foremost it is important to understand that adults with Down syndrome have the same need for healthcare as all other adults. The need for immunizations is the same, as is screening for high blood pressure, heart disease and thyroid issues. A healthcare provider should never automatically attribute symptoms solely to Down syndrome. As a healthcare advocate ensure that appropriate screenings and other diagnostics are completed. Because many conditions may have similar symptoms, it is also important to avoid leaping to conclusions that they are the result of the worst possible diagnosis. For example, Alzheimer's may be considered when a person shows signs of confusion or mood changes, yet those same symptoms occur in Hypothyroidism—a treatable condition.

The chart below lists common medical conditions seen in adults with Down syndrome. It is important to note that not every adult will encounter all of these conditions.

Many adults with Down syndrome will have thyroid issues. The symptoms of a thyroid condition, i.e. mood and weight changes, loss of energy and fatigue, among others, can easily be confused with characteristics of Down syndrome and other medical issues.

If an adult with Down syndrome loses interest in previously enjoyed activities or shows a decline in functional skills, he may be exhibiting signs of depression. Approximately 30% of people with Down syndrome show some signs of mental health problems, such as depression, obsessive-compulsive disorder or conduct disorders such as aggressive or destructive behaviors.

Hearing and cardiac issues are often identified in childhood, but may also first appear in adulthood. Therefore, it is important that auditory testing be done every couple of years and screening for heart valve problems be done at the annual physical.

Males should have annual testicular exams due to an increased risk for testicular cancer. Females should have routine breast and pap tests, if tolerat-

“Adults with Down syndrome should have all of the same age-appropriate preventive care as (the general population) in addition to special screenings.”

Patients with Down syndrome often present with behavior problems when they actually have underlying medical problems.”

Health Care Management of Adults with Down Syndrome, David S. Smith, M.D., American Family Physician, Volume 64, Number 6, September 15, 2001

ed. If not, the healthcare provider should determine the diagnostic value of the exam.

When an adult with Down syndrome begins to slow down or experience changes in behavior, skills, or health, it can sometimes be confusing. The good news is that with a better understanding of what is happening, adults with Down syndrome can continue to live productive and meaningful lives for many years.

This is the first in a series of articles on aging in Down syndrome. Future pieces will address healthy aging, quality of life, the stages of Alzheimer's, and palliative and hospice care.

COMMON MEDICAL CONDITIONS IN ADULTS WITH DOWN SYNDROME

Cardiology ¹

- Acquired valvular heart disease
- Mitral valve prolapse

Dentistry ⁵

- Periodontal disease
- Bruxism (Teeth grinding)

Dermatology

- Xerodermatitis (Dry skin)

Endocrinology ¹

- Thyroid disease
- hypothyroidism
- hyperthyroidism

Endocrinology ¹

- Diabetes Mellitus

Neurology

- Seizures
- Alzheimer's disease

Oncology ¹

- Testicular cancer
- Breast Cancer
- Cervical Cancer

Orthopedic

- Spinal cord compression
- Atlantoaxial subluxation
- Osteoporosis

Ophthalmology ²

- Cataracts
- Keratoconus
- Refractive errors

Otolaryngology (ENT)

- Hearing loss ²
- Obstructive sleep apnea
- Excessive ear wax

Psychiatry

- Depression
- Obsessive Compulsive Disorder
- Abuse (physical, emotional, sexual)
- Conduct disorder

NOTE: Not all adults with Down syndrome will develop all of these conditions.

Screening Frequency

.5 — every six months

1 — annual

2 — every two years

All others as needed



We're on the web!
AADMD.org/NTG

NATIONAL TASK GROUP ON INTELLECTUAL DISABILITIES AND DEMENTIA PRACTICES

The NTG is affiliated with the American Academy of Developmental Medicine and Dentistry and the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago.

Other partners include the

Center on Excellence in Aging at the University at Albany and the Gerontology Division of the AAIDD (American Association on Intellectual and Developmental Disabilities). The NTG is a member of *LEAD* - "Leaders Engaged on Alzheimer's Disease," a Washington-based coalition working to focus attention on Alzheimer's disease and related disorders.

For more information about the NTG, please visit the website.

AGING & DOWN SYNDROME RESOURCES

The **Advocate Adult Down syndrome Center** in Chicago has many **online resources** related to aging.

<https://www.advocatehealth.com/luth/health-services/adult-down-syndrome-center/resources/>

Overview of Aging and Down Syndrome, NDSS webinar video, 2013
https://www.youtube.com/watch?v=3yQc_7cjTDA

Health Care Management of Adults with Down Syndrome, David S. Smith, MD, American Family Physician, September 15, 2001
<http://www.aafp.org/afp/2001/0915/p1031.html>

Health Care Guidelines for Individuals with Down Syndrome, William I. Cohen, MD, Down Syndrome Quarterly, Vol 4, Number 3, September, 1999
<http://www.ds-health.com/health99.htm>

NTG FAMILY SUPPORT

In May 2016, the NTG began hosting a monthly online support group meeting for family caregivers. We have long recognized the valuable role family members play in supporting one another and are all constantly learning as we share our family stories. Support group participants and those who join us via email have expressed their gratitude for the opportunity to connect with others who are having comparable experiences. Over the past 1.5 years NTG members from a variety of disciplines have joined us for selected meetings and have shared their knowledge and expertise. Family caregivers have also noted the benefit of hearing from NTG members who specialize in Medicine, Occupational Therapy, Gerontology and Psychology.

There has been significant interest in the online support group. We know that there are likely many more families who are seeking answers or someone to just listen to them. We also recognize that to be effective, the online group must remain small.

Over the course of the next few months the NTG will assemble a small workgroup to develop a process to set up regional online support groups, organized by knowledgeable facilitators. In the meantime, the Alzheimer's Association has a 24-hour Call Center that families can access. A growing number of local Alzheimer's Association offices are becoming more informed about ID and Alzheimer's disease and may be able to provide family support more locally.

If you would like more information about the online support group contact, Jadene Ransdell at the email address listed in the resource section below.

NTG CONTACTS

For general information about the NTG:

Seth Keller, Co-Chair: sethkeller@aol.com or Matt Janicki, Co-Chair: mjanicki@uic.edu

For information about *Family Advocacy*:

Mary Hogan, Chairperson—Family Advocacy Workgroup: maryhogan@comcast.net

For information about *Family Caregiver Online Support Groups*:

Jadene Ransdell, Online Support Groups Facilitator: jadeneransdellaz@gmail.com

For information about *NTG Training*:

Kathie Bishop, Co-Chair—Education and Training Workgroup: bisbur1@earthlink.net

GOT IDEAS?

If you have an idea for a newsletter article, would like to share information, or have questions about the newsletter, contact the editor of the NTG Caregiver News at

ntgfamilysupport@comcast.net

